ICF based comparison of disease specific instruments measuring physical functional ability in ankylosing spondylitis

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EXTENDED REPORT

Objective: To link validated and widely used instruments measuring physical functional ability in ankylosing spondylitis to the International Classification of Functioning, Disability, and Health (ICF) and to compare their contents, based on the results of the linking process.

Methods: The Bath Ankylosing Spondylitis Functional Index (BASFI), the Dougados Functional Index (DFI), the Health Assessment Questionnaire modified for the spondylarthropathies (HAQ-S), and the Revised Leeds Disability Questionnaire (RLDQ) were linked to the ICF separately by two trained health professionals according to 10 linkage rules.

Results: All concepts contained in the items of the selected instruments could be successfully linked to the ICF except for “illness” included in the HAQ-S. Altogether 55 different ICF categories were linked. Seven belonged to “body functions”, 43 to “activities and participation”, and five to “environmental factors”. The component “body structure” was not contained in any of the four instruments. Only two ICF categories were common to all selected questionnaires, but there was a high level of concordance on the concepts represented in them. However, especially in terms of “activities and participation”, the emphasised aspects differed.

Conclusions: The ICF provides an excellent common framework for the comparison of disease specific instruments for ankylosing spondylitis. For a future revision of the ICF, a specification of major limitations in patients with ankylosing spondylitis is suggested.

Ankylosing spondylitis is thought to be the most common and typical form of spondylarthropathy. Pain and spinal stiffness, often gradually leading to severe impairment in physical functioning and quality of life, are regarded as the most important complaints and therapeutic challenges in this disease.

In 1998, during the OMERACT (Outcome Measures in Rheumatology Clinical Trials) conference, the members of the ASAS (Assessment in Ankylosing Spondylitis) working group selected “core sets” of outcome instruments to be applied in different kinds of trials in ankylosing spondylitis. Three core sets for three different settings were proposed. In all these core sets the ASAS recommended the obligatory use of the domains physical function, pain, spinal mobility, spinal stiffness, and patient global assessment.

Physical functional ability is assessed using self administered instruments. The Bath Ankylosing Functional Index (BASFI), the Dougados Functional Index (DFI), the Health Assessment Questionnaire modified for the spondylarthropathies (HAQ-S), and the Revised Leeds Disability Questionnaire (RLDQ) are among the most widely used, well established, and internationally recommended instruments for measuring physical functional ability in ankylosing spondylitis. However, all these instruments have both strengths and weaknesses.

When selecting or comparing instruments for measuring physical functional ability in a research or clinical setting, accuracy, feasibility, and discrimination need to be considered. However, because of the different spectrum of items covered by the instruments a comparison between them is difficult.

The newly available International Classification of Functioning, Disability, and Health (ICF, formerly ICIDH-2) offers a possible solution to this dilemma. The ICF belongs to the family of classifications produced by the World Health Organisation and represents a comprehensive common framework for describing functioning and health. Using established linkage rules, items included in physical functional ability measures can be linked to the best corresponding ICF categories. Accordingly, our objectives in this study were to link the BASFI, the DFI, the HAQ-S, and the RLDQ to the ICF classification and to compare the contents of these four instruments.

METHODS

Measures
BASFI
The BASFI is a self administered, disease specific instrument for ankylosing spondylitis, designed by a multiprofessional expert team of rheumatologists, physiotherapists, and research associates with a major input from patients. The final version, first published in 1994, consists of 10 questions altogether. Eight items concern activities referring to the functional anatomy of the patients, and two additional questions assess the patients’ ability to cope with everyday life.

DFI
The DFI is a self administered, disease specific instrument for ankylosing spondylitis designed by rheumatologists with special interest in ankylosing spondylitis and originally applied as an interview. The revised self administered...
component ‘‘body functions’’ is as follows: three, or four level categories. An example selected from the
of the so called categories. Categories are the units of the ICF
and fourth levels (one digit each). The component letter with
digit), followed by the second level (two digits), and the third
a numerical code starting with the chapter number (one
linkage study).

factors (e), and personal factors (which have not yet been
following components: body functions (b), body structure
major parts, each containing two separate components.
standardised common language. The ICF consists of two
of information about health and health related states in a
ICF
ing up and neck mobility’,’’ and ‘‘posture’’.10

HAQ-S
The HAQ-S is a self administered, disease specific instrument
for ankylosing spondylitis. It was built on the standard HAQ
designed for rheumatoid arthritis by adding five questions
relating to neck and back functioning. Those were identified
in a 1985 mailed survey of 300 British patients with
ankylosing spondylitis (Peer K, Loughborough University,
Nottingham, UK, personal communication, 1985). The HAQ-
S consists of 25 items.9

RLDQ
The RLDQ is a self administered, disease specific instrument
for ankylosing spondylitis. During the revision process of the
questionnaire a group of 12 patients with ankylosing spondyl-
itis was interviewed, all of whom were attending a three week
inpatient rehabilitation course. The RLDQ includes 16 items
grouped into four areas: ‘‘mobility’’, ‘‘bending down’’, ‘‘reach-
ing up and neck mobility’’, and ‘‘posture’’.10

ICF
The ICF15 was designed to record and organise a wide range
of information about health and health related states in
a standardised common language. The ICF consists of two
major parts, each containing two separate components.
Part 1 covers Functioning and Disability and includes the
following components: body functions (b), body structure
(s), and activities and participation (d).
Part 2 covers Contextual factors and includes environmental
factors (e), and personal factors (which have not yet been
classified and are therefore not taken into account in this
linkage study).
In the ICF classification, the letters b, s, d, and e—which refer
to the components of the classification—are followed by
a numerical code starting with the chapter number (one
digit), followed by the second level (two digits), and the third
and fourth levels (one digit each). The component letter with
the suffix of two, three, or four digits corresponds to the code
of the so called categories. Categories are the units of the ICF
classification. Within each chapter, there are individual two,
three, or four level categories. An example selected from the
component ‘‘body functions’’ is as follows:
• b2 Sensory functions and pain (chapter level or first level)
• b280 Sensation of pain (second level)
• b2801 Pain in body part (third level)
• b28013 Pain in back (fourth level).

Within each component, the categories are arranged in a
stem/branch/leaf scheme. Consequently, a lower level cate-
gory shares the attributes of the higher level categories to
which it belongs—that is, the use of a lower level (more
detailed level) category automatically implies that the higher
level category is applicable but not the other way round.

At the end of each embedded set of third or fourth level
categories, as well as at the end of each chapter, there are
‘‘other specified’’ categories (uniquely identified by the final
code 8). These categories allow the coding of aspects not
included in any other specific categories.15

Linkage of items to the ICF
Tables showing the linkage process for the BASFI, the DFI,
the HAQ-S, and the RLDQ can be requested from the
 corresponding author. All four selected instruments were
linked to the ICF separately by two trained health profes-
sionals according to 10 linking rules.16 The linking rules are
guidelines which enable concepts contained in health status
measures to be linked to the ICF in a standardised manner.
According to these rules, experts trained in the ICF are
advised to link concepts contained in a health status measure
to the ICF category representing this concept most precisely.
The most important linking rules are summarised below.
If one item encompasses different concepts, the informa-
tion in each concept should be linked. For example, in item 1
of the BASFI ‘‘Putting on your socks or tights without help or
aids (e.g., sock aids)’’ the concepts ‘‘putting on your socks or
tights’’, ‘‘help’’, and ‘‘aids (e.g., sock aids)’’ have been linked
to the ICF separately (see table 1).
If the content of an item is not explicitly included in the
corresponding ICF category—that is, the questionnaire provides
more detailed information—‘‘the other specified’’ option at the
third or fourth coding level of the classification has to be
applied.17 This can be illustrated by the fourth item of the DFI
(‘‘4, Can you get into a bathtub?’’) which was assigned to ‘‘d498’’—
that is, ‘‘mobility, other specified.’’ The additional information
has to be documented as well as the selected ICF code.
If the content of an item is more general than the correspon-
ding ICF category, the code of the higher level is
linked. This can be illustrated by ‘‘5a, Getting up off the floor
without help from lying on your back’’ of the BASFI which
has been linked to the chapter ‘‘e3’’ of the classification
(‘‘support and relationships’’, defined as ‘‘(…) people or
animals that provide physical or emotional support, nurtur-
ing, protection, assistance and relationships to other persons,
in their home, place of work, school or at play or in other
aspects of their daily activities’’).15

The abbreviation hc is used for concepts concerning a
health condition—for example, the concept ‘‘illness’’
included in the HAQ-S (‘‘How much stiffness have you had
because of your illness in the past week?’’).
To decide which ICF category should be linked to each item
in the four questionnaires, consensus between the two health
professionals was required. In case of disagreement concern-
ing the selected categories a third independent assessor with
expertise in the concept and taxonomy of the ICF and the
linking rules was consulted to make a final decision on the
most suitable code.
The percentage of cases in which the third independent
assessor was consulted for a final decision on the most
precise ICF category was calculated. In addition, the degree of
agreement between the two health professionals concerning
the component, first, second, and third ICF levels was
estimated by means of the k statistic17 and the corresponding
bootstrapped confidence intervals.18

The data analysis was carried out using SAS for Windows,
version 8.

RESULTS
Linkage process
All the 124 concepts contained in the items of the BASFI,
DFI, HAQ-S, and RLDQ could be successfully linked to the
ICF, except for ‘‘illness’’ contained in the HAQ-S.
The third independent assessor was consulted for 26 of the 124 concepts (21.0%). The results of the \( \kappa \) statistic, as well as the bootstrapped confidence intervals for the component, first, second, and third ICF levels are presented in table 1. The estimated \( \kappa \) coefficients ranged from 0.78 at the component ICF level to 0.98 at the first and third ICF level, respectively. The width of the 95% bootstrapped confidence interval, which indicates the precision of the estimated \( \kappa \) coefficient was narrowest at the third level and widest at the component ICF level.

### Table 2

<table>
<thead>
<tr>
<th>ICF domains</th>
<th>DFI</th>
<th>BASFI</th>
<th>RLDQ</th>
<th>HAQ-S</th>
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<tbody>
<tr>
<td>Body functions</td>
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<tr>
<td>b134 Sleep functions</td>
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<td>b280 Sensation of pain</td>
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<td>b289 Sensation of pain, other specified and unspecified</td>
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<td>b4402 Depth of respiration</td>
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<td>b450 Additional respiratory functions</td>
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<td>b7603 Supportive functions of arm or leg</td>
<td>( \times )</td>
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<tr>
<td>b7800 Sensation of muscle stiffness</td>
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<tr>
<td>Activities and participation</td>
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<tr>
<td>d410 Changing basic body position</td>
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<tr>
<td>d4100 Lying down</td>
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<td>d4101 Squatting</td>
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<td>d4102 Sitting</td>
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<td>d4104 Standing</td>
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<tr>
<td>d4105 Bending</td>
<td>( \times )</td>
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<tr>
<td>d4109 Changing basic body position, unspecified</td>
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<tr>
<td>d4150 Maintaining a lying position</td>
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<tr>
<td>d4152 Maintaining a sitting position</td>
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<tr>
<td>d4154 Maintaining a standing position</td>
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<tr>
<td>d4201 Transferring oneself while lying</td>
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<tr>
<td>d430 Lifting and carrying objects</td>
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<td>d4300 Lifting</td>
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<td>d4400 Picking up</td>
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<td>d4402 Manipulating</td>
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<td>d4452 Reaching</td>
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<tr>
<td>d4453 Turning or twisting the hands or arms</td>
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<td>d450 Walking</td>
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<tr>
<td>d4551 Climbing</td>
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<td>d4552 Running</td>
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<tr>
<td>d451 Driving motorised vehicles</td>
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<td>d498 Mobility, other unspecified</td>
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<tr>
<td>d499 Mobility, unspecified</td>
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<tr>
<td>d5 Self care</td>
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<tr>
<td>d510 Washing oneself</td>
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<tr>
<td>d5100 Washing body parts</td>
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<tr>
<td>d5101 Washing whole body</td>
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<td>d5102 Drying oneself</td>
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<td>d5204 Caring for toenails</td>
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<tr>
<td>d530 Toileting</td>
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<td>d5400 shampooing</td>
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<td>d5402 Putting on enemies</td>
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<tr>
<td>d5403 Taking off enemies</td>
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<td>d550 Eating</td>
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<tr>
<td>d560 Drinking</td>
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<td>d5709 looking after one’s health, unspecified</td>
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<td>d6200 Shopping</td>
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<td>d6300 Doing housework</td>
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<td>d6409 Doing housework, unspecified</td>
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<td>d6509 Caring for household objects, unspecified</td>
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<td>d6500 Remunerative employment</td>
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<td>d9209 Recreation and leisure, unspecified</td>
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<tr>
<td>Environmental factors</td>
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<tr>
<td>e1150 General products and technology for personal use in daily living</td>
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<tr>
<td>e1151 Assistive products and technology for personal use in daily living</td>
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<tr>
<td>e1201 Assistive products and technology for personal indoor and outdoor mobility and transportation</td>
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<tr>
<td>e135 Products and technology for employment</td>
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<tr>
<td>e3 Support and relationships</td>
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</table>

\( \times \) indicates that the ICF category was represented in the items or concepts of the questionnaire one or more times.
Altogether 55 different ICF categories were linked. Seven belonged to the component “body functions”, 43 to “activities and participation”, and five to “environmental factors”. The component “body structure” was not contained in any of the four selected instruments.

Throughout the linkage process we identified two ICF categories common to all four questionnaires.

**Linkage results**

The results of the linking process of the four selected instruments are presented in table 2.

All questionnaires covered the ICF components “body function” and “activities and participation”, whereas “environmental factors” were only represented in the BASFI and the HAQ-S.

Among the instruments selected, the HAQ-S was the one that could be linked to the most ICF categories (20) that were not contained in the others. Sixteen of these refer to “activities and participation”, two to “body functions”, and two to “environmental factors”. Further specific analyses of the structure and the contents of the questionnaires during the linking process showed that the DFI represented more items relating to “body functions” (3) than the other selected instruments.

As revealed by the linking process, the questionnaires showed a high level of concordance in terms of the domains of functioning and health they covered, though each includes different aspects. This applied especially to the component “activities and participation” of the classification.

All four instruments focus on the chapter “d4" (mobility), reflected in 23 different ICF categories, though each of these includes specific concepts. The DFI and the BASFI covers items that could be linked to the category “d410” (changing basic body position) and “d415” (maintaining a body position), whereas the HAQ-S focuses on mobility of the upper extremity, as shown by the terms “lifting and carrying objects” (d430), “manipulating” (d4402), and “turning and twisting the hands or arms” (d4453). The DFI, BASFI, HAQ-S include “picking up” (d4400), whereas the BASFI, RLDQ, and HAQ-S include “reaching” (d4452). The DFI, BASFI, and HAQ-S could be linked to “d4551” (climbing), while one item of the RLDQ was assigned to “mobility, unspecified” (d499).

The ICF concept “d5 self care” is represented in all four instruments. Items from each of them could be linked to the category “d5” (self care), with the chapter as a whole or the aspects “washing oneself” (d510) and “eating” (d550) included. The latter two are not incorporated in the other three instruments selected.

The RLDQ could be linked to four ICF categories referring to “self care” which are regarded as some of the clinically most relevant features in patients with ankylosing spondylitis.2 This may be because the selected instruments were explicitly designed to assess patients’ perception of their activities of daily living and not disease activities.10

The linking procedure showed that the DFI contains more items relating to “body functions” than the other three selected questionnaires. A possible explanation may be that the DFI was designed only by physicians7–8 as opposed to the other three selected measures which involved a major input from patients (HAQ-S, RLDQ) or from a multiprofessional team including physiotherapists and patients (BASFI).6

The linking process also showed that only the HAQ-S included “stiffness”, and none of the selected instruments represented “pain in the back”, which are regarded as some of the most commonly used self administered questionnaires for ankylosing spondylitis except “illness” (HAQ-S) has been possible, based on acknowledged linking rules.2

Three of these are identical (“e1151 assistive products and technology for personal use in daily living”, “e1201 assistive products and technology for personal indoor and outdoor mobility and transportation”, and “e3 support and relationships”). Additionally, the HAQ-S includes one item that could be linked to the e-component at a more general and comprehensive level than the BASFI (e135 products and technology for employment) as well as one further item linkable to the third level category “general products and technology for personal use in daily living” (e1150).

**DISCUSSION**

The ICF is very useful when comparing the contents of disease specific instruments for ankylosing spondylitis. Linkage to this classification of all the concepts included in the most commonly used self administered questionnaires for ankylosing spondylitis except “illness” (HAQ-S) has been possible, based on acknowledged linking rules.2

The degree of agreement between the two health professionals who carried out the linking procedure was high according to the k coefficient. However, estimation of the reliability of the linking process could be strengthened by increasing the number of raters in future studies.

By linking all four questionnaires to the ICF it could be shown that the classification is a very precise tool with few exceptions. This underscores the findings of Weigl et al.11

The precision of the ICF can be illustrated by, for example, items “19, to cough or sneeze” of the DFI and “coughing and sneezing” of the RLDQ, which can be transferred one to one to the ICF code “additional respiratory function” (b450) as they are included exactly in its definition.

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During the linking procedure another striking difference between the selected instruments measuring physical functional ability in ankylosing spondylitis becomes obvious. Whereas the BASFI and the HAQ-S include items and concepts referring to “environmental factors” of the classification, like “handrail or walking aid” (e1151 “assistive products and technology for personal use in daily living”), none of them is represented in the DFI and the RLDQ. A possible explanation for this could be the fusion of the expertise of a multiprofessional team and the experience of patients with ankylosing spondylitis.2

Although the linking procedure revealed a high level of concordance in the ICF concepts represented in the four selected measures, especially those concerning “activities and participation”, the aspects emphasised differ. The difference between the contents of the HAQ-S and those of the DFI,
BASFI, and RLDQ becomes obvious in the ICF categories referring to mobility of the upper extremity and self care, which are only applicable to the HAQ-S. A possible explanation for this finding may be that the HAQ was originally designed as a disease specific instrument for patients with rheumatoid arthritis and was modified for ankylosing spondylitis later on by adding five items to the rheumatoid arthritis version. In ankylosing spondylitis, peripheral arthritis leading to disability of the upper extremity and especially impaired hand and arm use is rather unusual compared with rheumatoid arthritis. This may be the reason why fewer ICF categories referring to mobility of the upper extremity are applicable to the other instruments. Presumably for the same reason, aspects of self care at a general level (d5) and especially the specific concept of “washing oneself” (d510) are represented in the HAQ-S, but not in the other selected instruments. This possible explanation is reflected in the fact that none of the five ankylosing spondylitis specific items of the HAQ-S could be linked to the chapter d5 of the ICF (table 4).

Although questionnaires assessing physical functional ability in patients with ankylosing spondylitis, such as the BASFI, the DFI, the HAQ-S, and the RLDQ, can be successfully linked to the ICF, the classification should not be regarded as a substitute for these instruments. In the future, it can serve as a common reference for all outcome measures. Some results of the linking procedure, however, may provide helpful arguments for a future revision process of the ICF—for example, currently the item “Looking over your shoulder without turning your body” of the BASFI and the concept “Are you able to look in the rear view mirror?” as well as “Are you able to turn your head to drive in reverse?” of the HAQ-S had to be assigned to the more general parent category “d498” (mobility, other specified”).

As involvement of the cervical spine leading to impaired neck rotation can be regarded as one of the most limiting impairments in patients with ankylosing spondylitis, categories exactly representing this concept could be added to one of the next versions of the classification. The latter also holds for the item “How much stiffness have you had because of your illness” of the HAQ-S. Spinal stiffness—one of the major complaints in ankylosing spondylitis—had to be linked to the ICF category 7800 (“sensation of muscle stiffness”), as the current version of the ICF does not include any other category closer to the sense of spinal stiffness.

The ICF based comparison provides information about the contents addressed in the different measures. Therefore, it can be a useful tool when selecting specific measures for a study. The first question when selecting measures is to decide what should be measured in consideration of the study end points, the population studied, and the planned intervention. The second question is to decide which measure to use. If one considers the contents covered in different measures, a selection based on the question “What should be measured?” can be made. Moreover, using the ICF as a reference framework allows a researcher or a recommending body to see which domains are covered in different measures. Therefore, it can serve as a guideline for the design of innovative disease specific instruments for ankylosing spondylitis.

Conclusion

The ICF provides an excellent common framework when comparing the contents of disease specific instruments for patients with ankylosing spondylitis. The linking process is a very valuable tool for making a detailed critical analysis of instruments for assessing physical functional ability, as it clearly shows which health domains are covered by them. For a future revision of the ICF, the specification of major limitations in patients with ankylosing spondylitis could provide a reference framework to define exactly what should be measured and which measures or items should be selected in detail to provide the most comprehensive picture of patients with ankylosing spondylitis. The ICF could then serve as a guideline for the design of innovative disease specific instruments for ankylosing spondylitis.

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